The committee convened at 11.02 am.

INQUIRY INTO VOLUNTARY ASSISTED DYING
Community Consultation Drop-in Session

Mr CHAIR: Ladies, we want to say thank you for coming to talk to us for a little while. The four of us want to say first of all that we acknowledge the traditional owners of this country, Bagala country, and we pay our respects to the elders past, present and emerging elders.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: My name is Tanzil and I am the Chair of the committee.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: These are my colleagues.

Mr YOUNG: Hello, I am Dheran Young. I am a member of parliament and represent the seat of Daly which takes in Daly River, Wagait Beach, Wadeye, Palumpa and all the way out to Dundee Beach.

The INTERPRETER: [Kriol spoken.]

[Multiple people speaking.]

The INTERPRETER: This is Margaret and she is an elder for the community. Mel Brown is a traditional owner and Jocelyn McCartney is another elder. The elders come to all the meetings and have gone to all the council meetings and (inaudible).

MARGARET: Same name like you.

The INTERPRETER: [Kriol spoken.]

Mr KERLE: My name is Matthew Kerle. I grew up in Batchelor. I am a member of parliament as well. I represent Moulden and Woodroffe in Palmerston.

The INTERPRETER: [Kriol spoken.]

Mr KERLE: I am part of the group, and we have come here today to listen to what you have to say.

The INTERPRETER: [Kriol spoken.]

Mrs CARLSON: Hi, I am Oly and I am a member of parliament. I represent Wanguri. It is next to Casuarina and the hospital; I am next door.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: Your mob know Lin. Lin will help us today with translation.

The INTERPRETER: [Kriol spoken.]

Unidentified speaker: (inaudible).

Mr CHAIR: We are here today to talk about voluntary assisted dying (VAD).

The INTERPRETER: [Kriol spoken.] That means …

Mr CHAIR: Help and choice to finish up.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: We know that talking about death and dying can upset; it can be very sensitive.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: If anybody feels upset or you want to have a break, we can have a break.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: The other thing is we are recording this conversation so that we can write it down and we can learn and we can write a report.

The INTERPRETER: [Kriol spoken.]

Mr KERLE: It is very important that what people say today is secret. We will not tell anyone that they said it unless they give permission.

The INTERPRETER: Whatever we talk here they will keep secret …

Mr YOUNG: No, sorry.

Mr CHAIR: We will clarify that.

Mr YOUNG: If you do not want it recorded, just let us know and we will take it off the recording.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: It is okay; Matt got a bit confused.

If something you are telling us you want that one private, you just tell us and then that one is private. That is the difference.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: Let us have a biscuit and we will play that Kriol recording, I think.

[Multiple people speaking.]

Mr CHAIR: Wait until everyone gets a biscuit first.

The INTERPRETER: [Kriol spoken.]

Mr KERLE: Let me know when you are ready.

The INTERPRETER: [Kriol spoken.]

[Kriol recording played.]

Mr CHAIR: Does everybody understand?

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: The first thing it would be good for us to know: what is the healthcare service like here now?

The INTERPRETER: [Kriol spoken.]

[Multiple people speaking.]

The INTERPRETER: To help them with their medication and take them into town for their doctor's appointments.

Mrs CARLSON: Is there a doctor here?

Unidentified speaker: A doctor comes every week or every fortnight to visit.

Unidentified speaker: The doctor usually comes only on Thursday.

The INTERPRETER: Every Thursday—every week or every fortnight?

Unidentified speaker: Weekly.

Unidentified speaker: Once a week.

Unidentified speaker: He comes from Katherine.

Unidentified speaker: I want the doctor to come and catch up on me here.

The INTERPRETER: But you have to wait for every week because the doctor only comes once a week. If they get sick any other day, they cannot see anyone until the doctor comes.

Mr KERLE: Does a nurse live in the community?

The INTERPRETER: [Kriol spoken.]

Unidentified speaker: Yes, we have two or three, Aboriginal worker.

Unidentified speaker: What about Katrina? Is she still here?

Unidentified speaker: Katrina still works here at clinic.

The INTERPRETER: They have one Aboriginal health worker and how many nurses?

[Multiple people speaking.]

The INTERPRETER: Two white nurses.

Mr CHAIR: Do those nurses or the doctors help with aged care, with elderly care? What help do you get?

Ms BROWN: Nurse and doctor mob, they help with old people.

MARGARET: One visit they come.

Ms BROWN: The old people walk from their house to the clinic.

Mr CHAIR: They do not visit in the house?

Ms BROWN: When there is an appointment for us, they come around and tell us to see the doctor.

[Multiple people speaking.]

Mr CHAIR: What about if someone is too sick, too old or too sick, do people come and visit?

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: They go to Katherine for palliative care then?

Unidentified speaker: When they are ready for finish, they catch the patient travel bus to Darwin from Katherine. When you have an appointment with the doctor, usually they call Brother Finnegan and then tell us we have to see a doctor in Darwin. They catch the bus to Darwin.

Unidentified speaker: Sometimes Greyhound bus.

Unidentified speaker: They have patient travel.

Unidentified speaker: The bus from Katherine Hospital goes every morning at 7.30 to Darwin, takes patients.

Mr CHAIR: You were telling me before about respite when we were talking about the respite. Tell us a bit about it.

Ms BROWN: The respite I was talking about. (inaudible) deliver meals on wheels, the brother from Beswick. (inaudible) ask her, 'How much is it?' They have to pay. Where can we find that money from our pension? All our money goes to income, we pay rent and what else do we pay—rubbish, power

Unidentified speaker: You mob pay for rubbish too, for picking up.

Unidentified speaker: Council mob.

Unidentified speaker: I end up with 350 or 400 that is for my (inaudible).

Mr CHAIR: Who cares for the elderly people when somebody is too old. Who cares for them here? Who looks after people when they are really sick?

Unidentified speaker: When they are really old and ready for finish, they stay up in town and get really old.

[Multiple people speaking.]

Unidentified speaker: (inaudible) but we are ready to go.

Unidentified speaker: (inaudible) come back home.

Unidentified speaker: They take them to town to Katherine Hospital or Darwin hospital and they just finish there.

Unidentified speaker: Generally they do not have a vehicle to (inaudible)

Unidentified speaker: (inaudible) cars to go in to be able to say their last goodbyes to them.

The INTERPRETER: Most of them do not get the opportunity to see them, like when they are already finished.

[Multiple people speaking.]

Mr CHAIR: Would you like people to be able to come home earlier if they are very sick to finish up?

The INTERPRETER: [Kriol spoken.]

Unidentified speaker: Yes, I know I did not get my mum to stay in Katherine Hospital. She stayed at home and I looked after her myself. She did not want to stay there.

Unidentified speaker: Like my uncle, right?

[Multiple people speaking.]

The INTERPRETER: They have an aged-care facility at Kalano in Katherine. My uncle was there for—I do not know—big long months. He was getting homesick and feeling in himself he wanted to come back, so now we have brought him back here. He said when he dies he wants to finish here. He does not want to go back to Katherine. He does not have any assistance. He will just finish in the house with no help.

Mr CHAIR: In that situation, would it help for your uncle, or someone similar, if they had more assistance to finish up? Is that something that ever happens?

The INTERPRETER: Only one stay over and bring him back now (inaudible). Like Mel was saying, only her mother she was the (inaudible) for Barunga. When she was ready to pass, Mel fought hard to bring her back home. She finished here. Some of the clinic staff—at that time we had good clinic staff there; good nurses that were reliable—used to go and give the pain relief and whatever. At the moment, Barunga does not have very good staff to assist, like nurses and that. Maybe they are understaffed; I do not know. I think there is a lot understaffed, everyone is. There are not enough staff to facilitate.

Mr CHAIR: When there are not staff sometimes other communities, they are using that teleconference—telehealth. Do you guys ever use telehealth?

The INTERPRETER: Sometimes when family is ready for finish. When the doctor mob from Darwin or Katherine want to talk to the family here. Do they do video link up (inaudible)? They talk through the video (inaudible)? Nothing.

Mr CHAIR: Not much—no? It does not happen here at all? No video at all?

The INTERPRETER: There are no resources or no-one to facilitate for it to happen.

Mr CHAIR: Okay. This council one, this video link—nobody uses this for that kind of thing?

The INTERPRETER: [Kriol spoken].

Unidentified speaker: When they have a council meeting they use the video to talk all the (inaudible) or nothing.

Mr CHAIR: When somebody …

Unidentified speaker: They call the local (inaudible) in the town if they (inaudible). They come on the video (inaudible).

Unidentified speaker: Yes, sometimes.

The INTERPRETER: I do not think it is very—we have the courts here. We cannot do video links. I come all the time. We have the court in here. When we have video links, we cannot—it does not (inaudible), it cuts out …

Mr CHAIR: It is not reliable enough.

The INTERPRETER: Yes, and we just talk through the phone if they are in another place. We just do the phone, on the mobile phone—no video links.

Mr CHAIR: Some doctors will tell us that if you use more video they maybe can help more—not just with VAD but also with healthcare. We were trying to work out how much they use this or do not use this. It does not sound like they use it very much.

MARGARET: When we have a doctor's appointment at the clinic …

Unidentified speaker: Yes, the clinic.

MARGARET: … maybe that doctor in Darwin, the specialist doctor, anything. You mob talk on the video sometimes?

Unidentified speaker: Yes, we (inaudible).

Mr CHAIR: Better to have translators for that?

Unidentified speaker: They have (inaudible).

Unidentified speaker: Just talk in English, Darwin.

Mr CHAIR: It must be hard.

The INTERPRETER: Doctors use big words and everything …

[Multiple people speaking].

MARGARET: Use wrong word …

[Multiple people speaking].

Mr CHAIR: It is hard when you cannot understand. We have Lin today, otherwise we would have trouble understanding.

The INTERPRETER: [Kriol spoken.]

MARGARET: (inaudible).

The INTERPRETER: [Kriol spoken.] I just explained if a doctor comes out and they want to talk in Kriol, they can ask. We can talk on the phone 24 hours. If it is an emergency, I can go to the hospital in the middle of the night.

Mr CHAIR: When was the last time somebody came home to finish up here?

The INTERPRETER: [Kriol spoken.]

Unidentified speaker: [Kriol spoken.]

The INTERPRETER: We had one at the start of this year.

Mr CHAIR: Was it hard to get him back in time?

[Multiple people speaking.]

The INTERPRETER: He was in the community because he did not want to go to town.

[Multiple people speaking.]

The INTERPRETER: They wanted to take him to town, but he would not go.

Mr CHAIR: He had cancer, we think? He did not get any cancer treatment; he just passed away?

The INTERPRETER: He just refused. I think they were just giving him the pain relief.

Mr CHAIR: Can somebody here, the clinic nurse, give some pain relief to help when people are suffering too much?

The INTERPRETER: [Kriol spoken.]

[Multiple people speaking.]

The INTERPRETER: Do they have a nurse? I do not think so.

Mr CHAIR: It must be very hard, though, if someone gets sick here nobody can help them with pain.

The INTERPRETER: We are not close to town. A lot of people suffer here, they do not get assistance.

Mr CHAIR: So if you are in Barunga, Beswick, Numbulwar—everybody just goes to Katherine? There is no help …

The INTERPRETER: If anybody is sick, they just send them to Katherine or Darwin. That many family who have passed in Katherine Hospital in palliative care. If they send them to Darwin and then they realise there is nothing more then can do—if they are from Beswick, Barunga, Bulman (inaudible)—they bring them to Katherine. That is the closest they can get to their home.

Mr CHAIR: We know in Darwin and in the Northern Territory a lot of people when they are very sick, they want support with VAD law. They do not want people to suffer, suffer, suffer. We know a lot of people want it, but not enough people have asked Aboriginal people and in communities what they think.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: The government wants to know whether this law will help people and whether Aboriginal people are interested in this law as well. We know a lot of Aboriginal people do not want a needle to finish up. That is okay.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: We also want to know if other people want choice—if they want to choose when they have cancer or a neurological disease; they are in a lot of pain. If doctors …

[Editor's note: recording stopped from 11.37.53 to 11.38.08.]

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: No, it is hard. Hard questions—that is why we are here.

The INTERPRETER: [Kriol spoken.]

MARGARET: The old people in Darwin hospital and Katherine Hospital, the doctor give them needle.

The INTERPRETER: Some people (inaudible) by choice.

Mr KERLE: They have to want it.

MARGARET: (inaudible) old people.

The INTERPRETER: Aboriginal people we do not like to …

MARGARET: Even if they have pain inside them. Family have to be there, just talking to them and holding their hand. When it is time for that person to give the family (inaudible) with no pain at all.

The INTERPRETER: She believes that they should just die on their own, not with assistance.

Mr KERLE: Is that only for Aboriginal people? What if this was …

MARGARET: [Kriol spoken.]

The INTERPRETER: [Kriol spoken.] She said if the white people want to do that then that is their choice. But we Aboriginal people we have the belief that we should finish on our own, like even if we are suffering and in so much pain, this is part of life for us.

Mr CHAIR: So now, what you are describing, having family around, holding hands, saying that time will pass, it sounds like you are explaining what is a good way to finish up. Finishing up is always bad, nobody wants to finish up, but what does a good death look like? What is a good finishing up for Aboriginal people?

The INTERPRETER: [Kriol spoken.]

MARGARET: [Kriol spoken.]

The INTERPRETER: At least when they die they cannot feel pain no more. We want them to finish on their own, not with—we never had this in our life before, so it is hard for us to adapt to this kind of stuff. When we know our family is going to finish, all the family get together. They go to the house where that person lives. Everyday there is more family coming because we have family spread out all over the countryside in different communities and it gives the families time to come in from other communities to say their last goodbye to them. They just sit with them until they are ready to finish on their own.

Mr CHAIR: In some places we have talked to they said they did not have enough time for somebody to come back to country. Does that ever happen here?

The INTERPRETER: Yes. Sometimes they bring them back or they do not even bring them back; they finish in the hospital. The preparation of bringing them home, they finish before they get back; they finish in the hospital. So they have to do all the paperwork and everything to bring them out of the hospital, bringing them back to finish on country. Some of them do not make it. They do not get the time to spend.

Mr CHAIR: It is hard.

Mrs CARLSON: A question from what you said before, finishing up and having family come. I just want to check if you wanted to come back early to finish up and spend your time, I am confirming that because there are not a lot of services and help here, that you are still okay with finishing up with that pain but as long as you are around family.

The INTERPRETER: [Kriol spoken.]

[Multiple people speaking.]

Mrs CARLSON: You know when it is time.

MARGARET: (inaudible). We just sit round with them, with that person and with the family. The kids are around there too. The kids can go outside and play, but the adults stay and start talking to the person.

The INTERPRETER: I suppose us Aboriginal people have adapted to this. We did not have …

MARGARET: (inaudible).

The INTERPRETER: In our culture too, when they are ready to die their spirit—we are very spiritual people. When they die, their spirit goes back to their country. That is another reason why we do not like the intervention with their death. It is a hard subject to talk about because we are spiritual people and it is hard to explain.

Mrs CARLSON: We went to Ngukurr and they have their cultural and spiritual background, but they also have religion. How strong is religion here—church?

[Multiple people speaking.]

The INTERPRETER: We follow the church leaders. They believe in the holy spirit and have a strong belief (inaudible). That is another reason why they do not want the (inaudible) intervention. We believe that when we are ready to die, God will take us. No one can intervene in that. Do you know what I mean? We are spiritual people in our culture and with our church.

Mr CHAIR: So the reason some people want this kind of law, this VAD law, is because they think it is actually compassionate and it is going to help somebody, Somebody who is suffering too much pain, they want to help.

The INTERPRETER: [Kriol spoken.] They want to help them to get rid of that pain so they can finish early, no more pain now.

Mr CHAIR: But even early, is not very early. This VAD is only for people who are dying, who have cancer.

The INTERPRETER: [Kriol spoken.]

Mrs CARLSON: No medicine can help them anymore.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: So if somebody still has sense—this is important—they have to give consent. They have to be able to say they want—if they already cannot say that, then they cannot have VAD.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: They have to ask not one doctor, not two, but three. The first time they ask the doctor, ‘Am I sick enough? Can I have this?’ Then they have to wait a little while. Then they ask the second doctor who checks if he is that sick and is he going to pass. Then if they agree, then next time, if the person can write and give consent, and if they give consent, then, only later, doctor and nurse can come and help somebody finish up.

The INTERPRETER: [Kriol spoken.]

[Multiple people speaking.]

Mr CHAIR: The reason we are saying that it is stages—it is a little different in some states and territories. Across Australia, everywhere except Northern Territory has a VAD law.

The INTERPRETER: [Kriol spoken].

MARGARET: [Kriol spoken.]

The INTERPRETER: [Kriol spoken.]

MARGARET: They make the law.

Mr CHAIR: Exactly.

The INTERPRETER: [Kriol spoken.] If everybody says no, they will stop them. But this is what they want from you mob, from all Aboriginal people—what we think about it. If we say yes or we say no.

Mr CHAIR: It is important to ask. Even if we know that Aboriginal people in community maybe they do not want to use this, is it okay if other people use this?

The INTERPRETER: [Kriol spoken]. What do you mob think? You mob think it is good for us Aboriginal people or no good. That is what they want to know. The more people that say yes, then they will fight to bring them in. The more people say no, then they will not bring this new law in. Just tell them how you mob feel.

When they want to sleep early, before they finish on their own, if they want help to finish early …

Mr CHAIR: Sometimes they also just want to finish not in hospital. Say if some Darwin mob do not want to finish in the hospital, then maybe they can go to their home and also be around family.

The INTERPRETER: [Kriol spoken.]

MARGARET: They are in Darwin hospital and they are ready to die, but they want to go back to their own house and die. This gives them the right to finish in their own house. If they bring this law in, anybody who does not want to die in the hospital—like me, if I die I want to die with my children (inaudible) and my grandson. I want to die in my own house; I do not want to die in a hospital. This will give us the right if they bring this law in. I think we need a break.

Mr CHAIR: That sounds good. A lot of talking. We are here all day.

[Multiple people speaking.]

The INTERPRETER: It is your own choice. If you want to finish (inaudible) this mob can help with that. If you finish in hospital it does not mean you have to get that needle.

MARGARET: If the doctor knows the patient is very sick …

The INTERPRETER: [Kriol spoken.]

Mr KERLE: When we write our report we might say the whitefella way, they might want to—whitefella might want to take the needle, but blackfella way, maybe we need to make sure that people, when they want to finish up when the medicine is no good anymore, come home to community and they finish up, none of this, but just around family. If you tell us that, we will put in in our report.

[Multiple people speaking.]

The INTERPRETER: [Kriol spoken.]

Mrs CARLSON: We still have to write in the report that is your preference.

The INTERPRETER: They want to know what all the Aboriginal people think about it. [Kriol spoken.]

MARGARET: We want to be close with them, holding hands and sitting around. The person has family.

Mr CHAIR: When people are close, holding hands, do you think it helps with their pain? Does it help them? Somebody who is suffering and if they are dying, and they are with family and community back here, does that help them? Does it help the person as well?

[Multiple people speaking.]

Mr CHAIR: Say that again.

Unidentified speaker: (inaudible).

Mr CHAIR: You do not want a needle either. Definitely I know you do not want a needle. I do not think I want a needle either. But what if somebody was very sick? They have come back from the hospital. They are back here with their family and with friends. Would it be okay if the sick person says, 'I am back; I am with family. I would like the needle now'? Would that be all right? Would that be possible? Who do they need permission from for that?

The INTERPRETER: [Kriol spoken.]

Mrs CARLSON: What do you think about that person? Is it going to cause a problem in the community …

The INTERPRETER: [Kriol spoken.]

.

Mr KERLE: They have to finish in a natural way

Mr CHAIR: If they wanted it, who would need to give permission—if?

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: TO, family, the …

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: I know, because you guys are the TOs and the elders. At all the council meetings you are the ones who help make decisions for a lot of things. We are wondering. In some other places some people said to us, if somebody wanted to make the decision for needle, they had to talk …

The INTERPRETER: [Kriol spoken.]

MARGARET: Even though I have pain inside me, I am happy to see my grandchildren. That would make me happy (inaudible).

The INTERPRETER: [Kriol spoken.]

MARGARET: When the whole family is there, it would be sons and daughters or maybe (inaudible) …

The INTERPRETER: That is the *junggayi*—our cousin, first full cousin.

MARGARET: [Kriol spoken.] There are too many suffering in silence (inaudible). We take him for coming back home town to see his grandchildren and children and family. That would make him happy.

Mr CHAIR: This law, the rest of the country—Victoria, South Australia, Queensland, everywhere—has except Northern Territory. Say in Victoria, maybe 400 or 500 people …

The INTERPRETER: Not many people. Victoria is a big place, but only 400 people do this now.

Mr CHAIR: Out of millions of people, only a few hundred use it. Even if this law happens for the Northern Territory, we reckon maybe 10, 20 people maximum …

The INTERPRETER: Even if they bring in this new law, not many people are going to use it—maybe only 10 people. It is a choice for the own person when they are ready to die. [Kriol spoken.]

Mr CHAIR: For some people—for cultural reasons, for religious reasons, for family reasons—they also do not want to finish up early. If somebody really wants, what we have to work out is if we can say no to them. We know some people are very sick and suffering and they do not have family members. They want to finish up early—'Enough. I now want to finish up early. I do not want suffer anymore.'

The INTERPRETER: [Kriol spoken.]

Unidentified speaker: I cannot do this no more. Too much this pain, I want to die now.

MARGARET: How can I live, you know? Tell the doctor to give the needle. That is what they will say. It is up to them.

Mr CHAIR: Is that okay with you if somebody else says that? Is that okay with you? Do you think that is okay? It does not upset you or offend you if somebody else can make a choice?

The INTERPRETER: If somebody else wants to do that in Darwin, you will not get angry or whatever if they want to do that?

[Multiple people speaking].

Mr CHAIR: We have some lunch coming soon. You guys want to have some lunch with us.

[Multiple people speaking].

Mr CHAIR: Lin, we want to say thank you to everyone for sharing.

The INTERPRETER: Thank you mob for coming and listening.

[Multiple people speaking].

Mr CHAIR: We will break and have some lunch.

The committee suspended.

Mr CHAIR: Because you can tell us a lot of things. We have already had half the conversation outside, so I will not tell you everything again.

Whenever we come out here, me and my colleagues always acknowledge country out here. We know this is Bagala people country, and we pay our respects to past, present and future emerging elders.

My name is Tanzil and I am one of the members of parliament in Darwin. There are 25 of us, but four of us are here today—my colleague Dheran

Mr YOUNG: Hello.

Mr CHAIR: A couple of the others out there I think have gone walkabout. They will be back, and we have Lin as well who is helping us translate.

We came out here to talk to people about voluntary assisted dying (VAD). We know it is upsetting for some people because we are talking about death and dying. We always say if anyone wants a break or does not want to talk or needs help, we can stop.

We are recording, with microphones, the conversation because we want to use the information to write our report. If you tell us anything that you want to keep private, you just tell us, 'I want that one to be private', and then we will not use that part.

The main reason we came out is because, like I was telling you outside, there was a VAD law in the Northern Territory back in 1995 and then they cancelled it and now they are trying to bring it back. Last year an independent group wrote this report and we have been asked to look into the report and the recommendations for a way for people to choose how they finish up better.

A model looks a bit like this. If somebody is real sick and they are terminally ill—dying, less than 12 months to live—they can go to a doctor and ask if they can have this, and have a first assessment. Then if they say no, then no, they can get an alternative. They have a second assessment with a second doctor after you wait a couple of weeks to check. If both doctors say yes, then you have to do it in writing and it has to be witnessed with consent. Only after all of that can somebody ask for a doctor and nurse team to come and help them with an injection to finish up. This is the rough model.

Every state and territory in Australia has one of these laws now, except Northern Territory. We have been asked to figure out how people feel about it, particularly in remote communities because nobody has really asked people in remote communities enough for us to know.

Why do you not tell us a bit about what you do health service-wise, palliative care, how people finish up at the moment?

WITNESS: In my community—I have been there for quite a long time …

Mr CHAIR: How long? Twenty years, wasn't it?

WITNESS: Yes, with my (inaudible). I had one palliative care patient there—that was back in 2011—an old lady. She got sick in Katherine, ended up in hospital. She found out that she had cancer spread. There was also another (inaudible) out there, but that was her first time that we had actually handled a palliative care patient back here.

It was hard because we were pretty close to that old lady. We did not have a nurse. We did not have a doctor on ground with us; it was just me and her.

When she came home, she came back home with (inaudible). What we did, me and the other aged care (inaudible), we got in contact with our manager out here, who was based here in Barunga. He came out; he helped us with another senior health worker. We sat down and we talked about it; how we can better make the patient comfortable after she comes home. We set up a plan. There was just four of us.

The patient at the house, she sat down and she told us how she felt and she did not want to go back into the hospital. We asked ourselves and the family—we got together there in (inaudible) nieces, nephews, sisters, brothers and her aunt, along with the four clinicians. We sat down with that mob of families and we explained to them her situation and that we asked the patient what she wanted. She did not want to go back to the hospital, so we got in contact with a specific doctor there in Katherine. We did a plan over the phone—there were four of us. Then we took it from there.

When the other two—the clinic manager and the senior health worker—came back here for something, (inaudible) stayed with her like that for the last two days we had with her because we set up—what we did was we would always get in contact with the DMO; that is the first thing we do. We talked to a DMO and she gives us advice over the phone and how much (inaudible). I still remember a little bit how I can do the palliative care plan in community if I do have another one.

So far, I have been looking at other families far away. I get sometimes calls asking for advice on how families can deal with them. I just lost a sister-in-law two days ago. She went back to Tiwi Islands and they were my daughter-in-law's mother. She went back home and passed away.

I spoke to her a few months ago when she first told me about this (inaudible). 'I got cancer', she said to me. I said, 'What? (inaudible) Are you sure? If you need some advice on how you want to deal with this, you can give me a call.' She said, 'I will', but it got …

Mr CHAIR: Spread.

WITNESS: Yes; it just came so fast to her. Then the last thing I knew she was back in Darwin hospital and she was going to return (inaudible). I told her to give me a call. I talked to her over the phone at the last minute (inaudible). I just cannot do anything now and I cannot (inaudible).

[Multiple people speaking.]

Mr CHAIR: Was she able to come back on country?

WITNESS: She did; she went back. Last week she went back on the island, stayed at her second-oldest sister's home, and that is where she passed.

Mr CHAIR: Where was that, which island?

WITNESS: Milikapiti.

Mr CHAIR: Was there anyone there to help with the palliative care at the end?

WITNESS: Yes. The clinic staff attended her every day.

Mr CHAIR: There is a good clinic out there, and has been for a long time.

WITNESS: (inaudible).

Mr CHAIR: The clinic here is not nearly as well set up as that one.

WITNESS: No. This one is—I do not know, but how I see it is, it is well set up here, but I am not from here; see? I come back and help whenever I can or when they need me, me and my driver out there. There are only two staff (inaudible).

Mr CHAIR: You are out from Eva Valley way—right?

WITNESS: Yes. Back this way on that main highway. Our mob there (inaudible).

Mr CHAIR: So there or here, what is the telehealth service like? Is it any good?

WITNESS: It is good, the telehealth service. It is really—when some patients do not like travelling and they like to just do it over the phone, talk to someone over the phone. Some patients do not like city lights—you know? They have too much of that bush life, and you know what they are like when they look at those movies and say, 'Oh yeah, look at (inaudible)'. I get that all right from my (inaudible) most of them are young ones. I say, 'But you need to go and see the specialist, the special doctor, for your condition. Organise the telehealth.' I get even young ones, 'I do not like them'. When I say, 'I would love to go to Darwin, just to look around'. Telehealth escorts, I like that.

Mr CHAIR: Is it better for the younger ones than the older ones, or is it about the same?

WITNESS: About the same because some young ones too—I have three young ones out there who do not like to travel to Darwin. They (inaudible) travelling. 'Can you do that video?', they say to me. I say, 'All right, I will try'. But when you get the doctor saying they would like to see them in person, they have no choice. I keep going back and always ask them or just say, 'Come on, go. It is good for you. The doctor wants to see your body language or how you are feeling. They can see it, just by looking at you. They cannot see it if you are talking on the phone.' Yes, I like that telehealth, that videoconference. It looks good too. Sometimes I will whinge and I will say, 'Come out on the ground', how we used to have it before.

Mr CHAIR: What was it like before?

WITNESS: Doctors used to come out to communities, see them in person, examine them there on the ground. But because of the coronavirus, that is when it all stopped. That was back in 2019.

Mr CHAIR: It was 2020, yes.

You just described that example of where you looked after somebody in palliative care. You were saying there was a DMO who used to …

WITNESS: Yes, always on.

Mr CHAIR: The DMO gave you instructions on pain relief as well?

WITNESS: Yes.

Mr CHAIR: You have managed that process yourself before?

WITNESS: Yes, with the DMO's advice.

Mr CHAIR: Of course, yes.

WITNESS: I managed it on ground.

Mr CHAIR: You cannot be everywhere, obviously. We both know there are not as many people on ground as there used to be.

With this, the whole idea is that there is the healthcare system, there is palliative care and now VAD would be a separate thing. We know that maybe only like 10 or 20 people every year in the Northern Territory would want to use it, probably mostly in the city. But we want to make sure if somebody wanted to use it out bush that we could make it available for them. Most people maybe would not want it.

One of the things we hear a lot about is whether or not people can come back on country to finish in time. Does that happen? Have you ever had challenges with getting people back in time? Do people come back from Katherine or Darwin in time to finish up on country?

WITNESS: No.

Mr CHAIR: They do not.

WITNESS: I only know of my one. That one I had at (inaudible).

Unidentified speaker: Most of them are in Katherine.

WITNESS: Most of them are always in Katherine.

Mr CHAIR: They get stuck there—right?

WITNESS: Yes, or Darwin.

Mr CHAIR: If you gave people the option to come back earlier, what kind of support would they need here for it to be enough? You probably cannot provide a hospital out here. What is enough to get somebody to come back and have choice to finish up better?

WITNESS: Mainly, all clinic staff always talk with families first. But sometimes we get the patient (inaudible) and say that they do not want to come back home. They want to stay in the hospital. I had my auntie do that.

Mr CHAIR: She not want to come back out country—interesting.

Everyone makes different choices; you cannot assume everyone makes one choice. People seem to make them all here different choices about pain relief as well. Some people have a very high threshold and do not need anything; other people want more. Do you have enough support and resources to manage pain out here?

WITNESS: Have it in the clinic, and when there is someone out here with it they will always have the resources set aside for that particular patient. When it is time for them to go and see that patient and that patient is in so much pain, give some pain relief (inaudible). There are always two clinicians go out to see that patient; it is never one. There are always two.

Mr CHAIR: This is particular when somebody's finishing up, you mean.

WITNESS: Yes.

Mr CHAIR: Okay.

That is the conversation we were obviously having outside as well, which I wanted to talk about in here because we are learning more now. Sometimes people do finish up with help on country, which we did not know much about before.

It is hard to talk about. We know these are very difficult things to talk about because death, dying, emotionally can be very triggering for people as well. We just want to make sure that we get as much information from people in remote communities as possible before anyone considers this law. Otherwise people will assume a lot of things. A lot of people have assumed that all Aboriginal people across the Northern Territory do not want to know about this—full stop. We are hearing slightly different things, a mix of things, so it is good to get an idea.

How long have you been doing this again, like 20-odd years—right? Because I remember Tony dobbed you in.

Unidentified speaker: (inaudible).

Mr CHAIR: He said you have got to talk to …

Unidentified speaker: (inaudible).

Mr CHAIR: Are there many like you who have been around working for a while out here?

WITNESS: Yes.

Mr CHAIR: (inaudible).

WITNESS: In Sunrise, there is about two—I think there is only me and Katrina.

Mr CHAIR: Who have been around for a while—right? Katrina was here earlier, wasn't she? Is she still in the clinic now?

WITNESS: Yes.

Mr CHAIR: I was trying to grab her as well.

WITNESS: Yes, she is there in the clinic. The others already helped us.

Mr CHAIR: How big is Sunrise's operation? How many places do you people cover?

WITNESS: You have got Bulman, Wugularr, here, Manyallaluk, Mataranka, Jilkminggan, Minyerri, Urapunga and Ngukurr.

Mr CHAIR: That is a fair spread. How many doctors in that?

WITNESS: They come and go—different doctors. I cannot keep up myself.

Mr CHAIR: Has anyone stuck around for a while? Once upon a time there would be one odd doctor who would have been around for 10 years, but lately I never hear that story.

WITNESS: (inaudible).

Mr CHAIR: Been around for, what, a couple of years, less than a year?

WITNESS: Two or three years.

Mr CHAIR: A few years. Do you guys interact much with the doctor or is the primary care that you are doing mostly a nurse network?

WITNESS: Doctors are involved, but when it comes during—we have specific doctors cover specific areas. With Barunga and Manyallaluk we have one doctor and then you have got another doctor covering Wugularr and Bulman.

Mr CHAIR: Are these guys remote rural generalists?

WITNESS: Yes.

Mr CHAIR: They are rural generalists.

WITNESS: And it is always telehealth.

Mr CHAIR: When we were talking with a couple of TOs here earlier, they remembered doing a bit of telehealth but they were saying even when they do the telehealth, they very frequently do not have a translator—sorry; I was pointing (inaudible). Does that happen often?

WITNESS: Out here they need a younger person if it is an older person that is being seen after hours. If they get them to the clinic sick in the early hours of the morning, I reckon they should have someone there alongside of them that can speak on behalf of them.

Unidentified speaker: (inaudible).

WITNESS: I do not really know. It is still the same system for Manyallaluk here. But when I am here helping out, I speak (inaudible) the same language.

Mr CHAIR: This is a bit more of a broad question, but you have been around a while doing this. We are all in the Territory for a long time as well—20, 30, 40 years, whatever. I came out here 20 years ago and this place looked different than it looks now. Some things look a bit better, some things do not look as good. Do you have a sense of whether things have gone backwards or forwards on primary healthcare, whether it was better back in the day, whether things are better now? Just any general reflections are useful.

WITNESS: I reckon it was better back in the day.

Mr CHAIR: Yes. Matt and I think that a little bit sometimes about some of these things as well. Do you have reasons for why?

WITNESS: Better staff (inaudible).

Mr CHAIR: Better staff; right.

WITNESS: We communicate, having that team working together. It is like you are doing everything on your own nowadays. I (inaudible) on my own anyway for the past 10, 11 years.

Mr CHAIR: It is hard work even in a team and by yourself it is even harder. We know the whole Northern Territory, the whole country, has not enough healthcare workers. We know that. That is why we are also interested that if we start something new like this, what extra help does that need to have?

WITNESS: I reckon we do need more hands on ground. I think with things happening in remote we should have some more.

Mr CHAIR: With palliative care, your best closest bet is Katherine, Kalano—right?

WITNESS: No, Katherine Hospital.

Mr CHAIR: Katherine Hospital is it?

WITNESS: With those old ones, you know how they go to aged care?

Mr CHAIR: Yes.

WITNESS: I was looking at how they look after healthcare patients. In aged care they have their own doctors …

Mr CHAIR: Some of them do, yes.

WITNESS: … (inaudible).

Mr CHAIR: Some do, some do not. There are different aged-care set-ups, mostly in the bigger places, Darwin, Tennant and Alice Springs—that sort of thing. They have different levels of service, but, again, a lot of the time they are also mostly nurses, fewer doctors. Usually, they will get a doctor's surgery from outside to come in and help service that aged-care facility—have one clinic attached to one aged-care facility.

Do you have many people from here who end up back in Darwin or Katherine in aged care? Nobody …

WITNESS: Not that I know of from Barunga.

Mr CHAIR: No, not so much.

WITNESS: I do not know. I am based in Manyallaluk 24/7. There is not much there in Manyallaluk community. I never had that.

Mr CHAIR: Yes, I would not have thought there is—it is hard to get spots in aged care, so going from bush to aged care is even harder, I would think. It is always useful to know.

WITNESS: Yes, because I am getting (inaudible) NDIS (inaudible) more than that team would be—there are four of those oldies out there that I want to try and help them all, getting support for them. They keep knocking me back. Oldies are putting (inaudible).

Mr CHAIR: NDIS providers, is there a good one, as well, to know about?

WITNESS: Yes.

Mr CHAIR: Do you have enough of them to cover what we are looking for? Where are the biggest shortfalls?

WITNESS: I have not tried them yet.

Mr CHAIR: The NDIS footprint here is pretty minimal?

WITNESS: Yes. (inaudible) palliative care thing (inaudible). I would like to try one day with them—sit down with them and get more information off them. If I do come across this situation again, hopefully they would help me out. They would give me a lending hand.

Mr CHAIR: I am partly asking you because I know you are a healthcare worker; you have been involved for a long time; I am not asking you to speak on behalf of your community, country, clan or tribe. I am asking you personally, how do you feel about voluntary assisted dying laws? Even if you would not use it, how do you feel about if other people might choose to use it? Are you okay with it? Does it offend you? Is choice okay for you?

WITNESS: It is all right with me.

Mr CHAIR: It is all right with you? Okay.

WITNESS: Yes.

Mr CHAIR: Why?

WITNESS: Because I have not actually come across this yet.

Mr CHAIR: No, that is all right. The point is the Northern Territory is the only place that does not have a voluntary assisted dying law. We know that a lot of people in the city, there is a lot of support for people who want—if they are terminally ill, incurable, a doctor would agree—to finish up, maybe outside of hospital surrounded by family, get that injection, that sort of thing. We know there is support for that elsewhere, but we also want to check, even in places where maybe there is not as much support for it, if people are okay with other people having a choice or should it just be no. Some people, maybe on religious grounds or cultural grounds, sometimes they just say no. Then there are other people we find who say, 'I do not mind. I do not want to use it, but people can have a choice.'

WITNESS: Yes. It is their choice.

Mr CHAIR: That is useful to know as well. There are a lot of people who do not think that there is any support in Indigenous communities for people having choice, even. It is useful for us to learn.

WITNESS: Yes, it is their choice.

Mr CHAIR: The reason people introduced these laws is to have—if you could have one—a good death; to die in a good way. What, for you, is a good death? It is a hard question.

WITNESS: Yes, it is hard. I do not know.

Mr CHAIR: Surrounded by family, countrymen, (inaudible)—any of these things you can think of.

WITNESS: Yes, I reckon to just be surrounded by family and any person that you trust.

Mr CHAIR: People you trust, yes. Does that include being surrounded by doctors and nurses, or does it matter or not matter?

WITNESS: It really does not matter.

Mr CHAIR: It does not matter.

WITNESS: No.

Mr CHAIR: At the end it is more important to be surrounded by loved ones and in the right place.

WITNESS: Yes.

Mr CHAIR: Which might be a possibility for some people, but maybe not hospital for everyone?

WITNESS: No, I reckon home is better for everyone, surrounded by family, with their loved ones.

Mr CHAIR: I know you have to go and pick up and drop off patients. I do not want to keep you forever. I want to check with you guys. Did you want to chip in? We started talking and my colleagues turned up—smoko break. No, I am just joking. They were just outside for two seconds.

Mr KERLE: No, that is really good.

Mr CHAIR: Thank you for taking time; I really appreciate it. It is very useful, honestly. If we can get every one of these conversations with us, it helps us understand a little bit better; it really does.

Mrs CARLSON: What has made you stay in your field for so long? Why have you stayed working in this field for so long? I am curious.

WITNESS: I do not know, to be honest.

Mrs CARLSON: How do we encourage young ones to do this?

WITNESS: I have tried that for many years.

Mrs CARLSON: We will work on it.

WITNESS: Yes. To be honest, I did not think of anything; I just continued what I was doing.

Mr CHAIR: You are doing good work, so you know where you are needed. Speaking of longstanding colleagues, your other colleague over there—what was her name again? Francine? No.

WITNESS: Katrina.

Mr CHAIR: Katrina, I am sorry. I do not know why I had ‘Francine in my head. Before you go, do you want to wander over and see if we can twist Katrina’s arm to come over and have a chat with us as well?

WITNESS: If we can catch her.

Mr CHAIR: We would have a better chance with you asking her than just me. Why do we not take a wander and see if we can get Katrina?

WITNESS: Yes.

Mr KERLE: There is another woman outside. She came back and she wants to talk.

Mr CHAIR: Great; all right; fantastic. Let us have a look at who is outside and then also see if we can grab Katrina as well. Thank you very much.

The committee suspended.

Mr CHAIR: My name is Tanzil. These are my colleagues, Oly and Matt. All of us are members of the parliament. We are three of the 25 members. We also have Caroline, Georgia and Katie helping us as well.

First of all, when we come out here we always acknowledge country. We know we are on Bagala country and pay our respects to elders, and we have come out here as well.

We are very grateful to everybody who will talk to us because we are here talking about something pretty difficult. We are here talking about death, dying, VAD (voluntary assisted dying). We know it is very hard for a lot of people. It is the same thing; when we are talking, if you want a break or you get upset or whatever, then we can stop. You just say whenever you want to stop, if you want to stop talking about stuff. We are recording this meeting so that we can use it to help us to write our report. If you tell us anything that you want to keep private, just tell us and then we will make sure we cut that. That is the main thing.

We are here because, last year, this report was written. A bunch of doctors, lawyers, healthcare professionals wrote this report. It is basically about how to give people help and choice to finish up. In every other state and territory in Australia, there is a VAD law to help people finish up. If they are sick and dying—no more treatment, they are in a lot of pain—then if they can get a few doctors to agree. You get one doctor to agree, then you have to wait a bit. Then another doctor to agree, have to wait a bit. Then you have to write and give consent. Someone has to witness it. If you do all of that, then a doctor and a nurse can come and help you with pain relief. They can give you an injection and help you finish up if you want.

We know not everybody wants this, but most people have not asked Aboriginal people and people out bush how they feel about it. We want to know how people feel about it. Anything you can tell us about the healthcare system, palliative care, aged care and the community—any of that is useful for us to know.

DELMA: Sometimes for us Aboriginal people, we do not want our old people to be in the aged care because we do not know what is going to happen with them in aged care. (inaudible) take care of them or get cheeky with them. I remember one of my cousin-sisters. She was in aged care. She fell off the bed and then she went to hospital, really to pass away.

Mr CHAIR: Oly and I both had grandparents in aged care and palliative care. I remember my grandma was in aged care and they treated her very well. Sometimes people are worried about things like that.

DELMA: That is why I cannot send my mum to the aged care. She came here earlier.

Mr CHAIR: Yes, we remember.

DELMA: We get to look after her ourselves because I use to be a health worker too.

Mr KERLE: Were you an Aboriginal health practitioner (AHP)?

Mr CHAIR: What kind of health work were you doing before?

DELMA: I was a health worker in this …

Mr CHAIR: In the clinic.

DELMA: The old clinic—looking after people, checking their blood pressure and giving them medicine if they got sick.

Mr CHAIR: Did you look after a lot of old people?

DELMA: Yes. I was working at the aged care (inaudible) but I was the health worker. I know what it is like working at the aged care.

Mr CHAIR: Did you work with people who were so sick they were going to finish up?

DELMA: Yes.

Mr CHAIR: Many of them? It sounds like you have done a lot. Have you seen a lot?

DELMA: Yes.

Mr CHAIR: Who helps people here when they are really sick? When people are really sick, will they be helped at the end? Who does that in this community?

DELMA: At the medical clinic but the family come together and they talk to the doctor. If they want their relative to come home to finish up, that is what Indigenous people do around this area. Sometimes the doctor says to us to go to Darwin and that is when the person is ready to—they tell us to switch the machine off (inaudible) in ICU.

Mr CHAIR: So, you have dealt with lots of people then, it sounds like, who were finishing up or very sick at the end. Have you also dealt with helping with medicine to stop the pain, pain relief medication? When people are really suffering and really sick (inaudible) like morphine, and they want like pain medication, were you involved with any of that when you were a healthcare worker?

DELMA: Yes, some people said they (inaudible) the tablet. Yes, and we just wait. Sometimes they just let people stay the way they are and they (inaudible) and ready to (inaudible).

Mr CHAIR: Delma, do enough people get to come home and finish up or do they all end up dying in hospital?

DELMA: A lot of them passed away in hospital. Sometimes they passed away unexpectedly.

Mr CHAIR: Do you think more people would want to come and finish up at home if they could?

DELMA: Yes, some people do. They make their decision to come back home and finish up.

Mr CHAIR: Who decides that—just the patient or also the family?

DELMA: The doctor talks to the families, but they decide, and then they talk to the patient too.

Mr CHAIR: Which family members?

DELMA: Mother, father, maybe if there is a whole family, your husband and your kids.

Mr CHAIR: Do *junggayi*s and things like that come into it?

[Multiple people speaking.]

DELMA: *Junggayi* are people in our culture and law and they decide too, sometimes, but most of all we have the relatives to decide. Their mother and father or their (inaudible) birth children make decision or their sons and daughters.

Another thing, when we call, say if you have distant family in the hospital, say, from my mother's sister kid and we want to call to find out to get information, if she is getting any better or whatever, and they turn around and say to us 'only family member'. You have to call particular family to let you get information. That is what the doctor said to me last week. I was calling for my cousin-sister because I was up in Darwin to see her when I came back from Queensland. Then when I came home, I wanted to call but they said you have to call her father. I said, 'How can I contact him? He does not have a number.' I told that doctor, 'I have just been there to see my cousin-sister and I am back to Roper and I want to find out how she is'.

Mr CHAIR: But they would not tell you.

DELMA: They would not tell me because …

[Multiple people speaking.]

DELMA: They all grew up in one house. My younger sister, her mum passed away, my mother's sister, and she was under my mother's care.

Mr CHAIR: I understand what you mean. Those clan and cultural systems, people do not recognise that in the healthcare system for you.

DELMA: Yes.

Mr CHAIR: You call and they will say, 'No, you are not the right person. You have to speak to the father.' Does that problem happen very often?

DELMA: Yes, it happens all the time.

Mr CHAIR: If you need to make a decision together, that must make it very hard to make decisions about whether someone should stay or come back to country or even what type of treatment they have. Does that make it complicated to help with the healthcare?

Did I make that clear? Lin, can you help me with that one? I was trying to say if you cannot get through to the right person, it must make it challenging to make healthcare decisions. Is that right?

The INTERPRETER: [Kriol spoken.] They say you have to be immediate family, but we class that person as immediate family. To (inaudible) we are not immediate family, but in Aboriginal way we are immediate family—from our mother's sisters kids they are brothers and sisters too. We call them mum too—our mother's sisters. We call them mum. Our father's father, we call them father too. We are all close. Even our aunties and our cousins, we are all close. We are not like non-Indigenous people. They can be straight cousins, but they are not that close. Do you know what I mean?

Mr CHAIR: Yes.

If there was a new VAD law, if there was this finishing up law, we know many people would not choose it. That is okay; it is a choice. If somebody wanted to choose it here, who would they need to consult with?

The INTERPRETER: [Kriol spoken.]

DELMA: (inaudible) blood family. That person who is blood family, whatever they decide.

Mr CHAIR: How many people are we talking about? Clan leader, *junggayi*—how many people have to say yes? Who decides together? I know you said blood family, but which ones exactly?

Unidentified speaker: [Kriol spoken.]

The INTERPRETER: [Kriol spoken.] It depends. If their mother and father are already dead, whoever grew that person up, they are responsible. Whoever took responsibility when their parents died, that is the person they have to go to. Or the grandmother, if the grandmother, grandparents, are still alive. The immediate family …

Mr CHAIR: One blood line.

The INTERPRETER: Yes.

Mr KERLE: What if all the people who grew that person up—because they are really old—are not with us anymore?

The INTERPRETER: Whoever is their *junggayi*. Whoever is the full cousin for them. We are born with a skin. We have a skinship(?) we are all born from. Our mother gives us our skin name. We follow the skin. Whoever is our cousin with the same skin, even if they are not blood related to us, but they have the same skin as our cousin, they are the boss of us. If we have got no other living family left, they take over responsibility.

Mr CHAIR: The last (inaudible) if somebody is elderly and let us say they have got no parents who brought them up, no cousins left, who is left to give that?

The INTERPRETER: The skinship.

Mr CHAIR: Kinship does that.

The INTERPRETER: Where we get our skin from. That is how we know we related. We are born with the skin and we have the straight skin who we can marry. We have skin for our brothers and sisters; we have one skin. Our cousins have another skin. Our cousins are the ones who are responsible. They can be an old lady, but they have a …

Mr CHAIR: Younger cousin.

The INTERPRETER: … younger cousin from the skinship. Like me, I have daughters that are old ladies, probably grey even, but they call me mum because of the skinship. We could have old people and young people calling each other mum, dad, auntie, cousin, whatever, because of the skinship. That is how our culture is. We follow that skinship.

Mr CHAIR: Even outside of VAD, the finishing up law, when you are making medical decisions, healthcare decisions, does the kinship help make those decisions together?

The INTERPRETER: [Kriol spoken.] Cousins from long distance, they can make the decision—there is always someone.

[Multiple people speaking.]

The INTERPRETER: Aboriginal people, we have always got family there. We are never going to run out of family. We have extended family from the skinship. It goes back to skinship.

DELMA: We have family everywhere. We have got family in another community.

Mr CHAIR: Delma, on another note, you put the message out for us the other day in Kriol—right? Did anybody respond to the message? Did anybody say anything to you about the message?

DELMA: No, but then you heard them. Like I said today, 'If you want to go and see them mob, they will be at the office. If you come up with any ideas, answer their questions.'

Mr CHAIR: We know a few people heard the radio there. We know some people heard the message

DELMA: When I do my network show, there are 29 communities (inaudible) Northern Territory. That is my network show every day Monday to Friday.

Mr CHAIR: The message got out there, so that is good.

We talked to some people today. The people we have heard from so far, a lot of them say, 'If you are making that finish up law, I do not want to use it', but a lot of people say, 'If someone else wants to use it, it is okay. It is their choice.' What do you think? Do you think it is okay for other people to have a choice with a VAD law?

The INTERPRETER: [Kriol spoken.] How do you feel?

DELMA: People have their own choice …

The INTERPRETER: But if they want to have the needle to finish early? [Kriol spoken.]

[Multiple people speaking.]

Unidentified speaker: Some of us would just leave that person as it is, after he or she passed away.

DELMA: Most of the time, especially when the doctor says, 'We cannot do anything now'. We just ask them if they can send them back home, or the family goes up there and spends a couple of days in the hospital and then they passed away.

But if we have family pass away in the community at home, we are not allowed to ask anybody to remove that body. We have to wait for our *junggayi*. Our *junggayi* people come and …

Mr CHAIR: They would move the body.

DELMA: They move the body and put it in the (inaudible).

Mr CHAIR: Yes. We understand that.

We are also trying to understand if people can get back to country fast enough when they want to finish up, or do they need more time to come and finish up in the community? A lot of people are passing away in the hospital.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: I am trying to figure out if there is enough time when the doctor or nurse says that somebody can come back to country. Do we need to give more time for people to come back to country?

DELMA: The doctor usually says to families …

Mr CHAIR: When they say that, how much time usually is left?

The INTERPRETER: When they are ready to finish, how long the doctor gives you mob to bring him back home?

DELMA: [Kriol spoken.] Sometime the doctor sends the family back home.

The INTERPRETER: How much? Do they give you one week, one month, to bring them back home?

DELMA: A couple of days or one week.

Mr CHAIR: Only a couple of days?

DELMA: Only a couple of days. That is what has been happening. That is what I see happen here.

Mr CHAIR: A couple of days is not a lot of time if everybody has to come and visit, you want to say goodbye. We are working out what is a good time. Is it one week, one month? What time should we give people to come back to country?

DELMA: Maybe give them one week.

Mr CHAIR: Yes, one week. A bit longer?

DELMA: Yes.

The INTERPRETER: Because we all have got family. You have got family in Bulman, Ramingining, (inaudible). We have to give it time (inaudible). They should give us maybe one month or two months so they can come.

Mr CHAIR: A bit longer, anyway, than one or two days. One or two days is not a lot of time.

The INTERPRETER: Because we have family everywhere.

DELMA: My sister passed away at our house. We had to wait till my *junggayi* came from Bulman. He was travelling all the way from Bulman (inaudible). Daryl and Leon came when Nancy was (inaudible). We had to wait for our *junggayi* to turn up.

Mr CHAIR: How long did you have to wait until the *junggayi* came? How long did it take, though?

The INTERPRETER: Probably four hours, five hours.

DELMA: It depends how fast they drive.

Unidentified speaker: That is a really bad road.

Mr CHAIR: I was trying to work out if it took them a long time to come afterwards or not.

The INTERPRETER: It depends too if they have got fuel, if they have got a car—all these things they have to.

DELMA: Most of them do not have a car, so they have to borrow a car to get here and organise themselves to come. If they give them time, like they say, 'You don't have to come now. She is getting more weak, weaker and weaker', give them a week or something, but most of the time everybody is busy grieving then and worrying about that until the person actually dies. Then they start organising for everybody to come here.

Mr CHAIR: Delma, you do radio—a big radio star. Do you ever use the telehealth, the video, for youth clinics?

The INTERPRETER: Video link. [Kriol spoken.]

DELMA: I broadcast here on the radio.

Mr CHAIR: When it comes to a doctor's appointment, do you ever use the video, telehealth?

DELMA: At the clinic, yes, we use that.

The INTERPRETER: When the doctor is in Darwin, specialist doctors sometimes …

DELMA: Yes, the doctor by video link.

Mr CHAIR: So you do talk to the doctor on the video link; you have those meetings.

DELMA: Yes.

Mr CHAIR: When you do that, is there a translator like Lin, an interpreter?

The INTERPRETER: Talk in Kriol.

DELMA: I do not know if they have got an interpreter.

Mr CHAIR: Have you done a doctor appointment with video link?

DELMA: Yes.

Mr CHAIR: You have done one.

DELMA: I have done one, but I did not have an interpreter.

Mr CHAIR: You did not have an interpreter.

DELMA: I answered the questions myself.

Mr CHAIR: Your English is pretty good.

[Multiple people speaking.]

Mr CHAIR: The telehealth, the video link, you have done it, but no help, just by yourself, you and the doctor, no interpreter.

DELMA: No interpreter.

Mr CHAIR: Is there ever an interpreter?

DELMA: Yes, they use the interpreter. I think they get someone who …

Mr CHAIR: Sometimes.

DELMA: … interpret for people.

Mrs CARLSON: If you need it.

DELMA: Yes.

The INTERPRETER: Not as much as they should, but …

Mr CHAIR: Yes, not as much as they should, but sometimes there is an interpreter.

DELMA: Yes.

Mr CHAIR: Delma, do you think people need more help to finish up on country? Should the doctors or nurses or the government—do Aboriginal people out in the bush need more help to finish on country or is it not a problem?

DELMA: Not a problem here.

Mr CHAIR: You think it is all right?

DELMA: Yes.

Mr CHAIR: So long as they can get back in time, they do not need that much help. What do they need? What do you need for a good death? To finish up good, what is the best way?

The INTERPRETER: [Kriol spoken.] When family comes back, more support from the clinic mob or doctor mob or who?

Mr CHAIR: Medicine—can you get medicine enough? Is it too hard to get the medicine?

DELMA: I do not know.

Mr CHAIR: That is okay. You do not have to know everything.

The INTERPRETER: There is only one thing. She lost two sisters, this one, but they finish quick. It was not really expected, when they were sick.

DELMA: [Kriol spoken.]

The INTERPRETER: [Kriol spoken.]

DELMA: What did I do?

The INTERPRETER: They still support you mob for medicine and everything (inaudible).

DELMA: Yes, that is what the nurse would do. She would come here. That was Barunga Festival time. She would come and treat my sister with medicine. Then she had a talk with me that she was not supposed to—because she came from hospital, from Katherine, and had come back to Barunga for the festival. Then the nurse told me she was not allowed to come out here …

The INTERPRETER: Discharged from the hospital.

DELMA: Yes. I said, 'Can you just explain to me what is going on?', to that nurse. Then she told me, 'She is going to pass away any day'.

The INTERPRETER: She has not got long to live.

DELMA: There were two of my sisters who passed away during Barunga Festival. My eldest sister and my third (inaudible). She had so many pain on her body and she was not allowed to come out of hospital (inaudible).

The INTERPRETER: She ran away from them.

DELMA: She ran away, yes, and came to Barunga Festival.

Unidentified speaker: They would not let her.

Mr CHAIR: So she came out of hospital? She ran away from the hospital?

DELMA: Yes, she ran away from Katherine Hospital. Maybe she was feeling herself that she was going to …

Unidentified speaker: She knew that she was going to die.

DELMA: She had to run away and come back and pass away in the house.

Mr CHAIR: How old was she?

DELMA: She was not that old. She must be 49.

Mr CHAIR: Not too old.

DELMA: The age of 49. I am 52 now.

Mrs CARLSON: Can I ask what she passed away from?

Mr CHAIR: What made her sick?

DELMA: She was diabetic. She had all that pain on her hip. Maybe her (inaudible) damaged her hip (inaudible), yes.

Mrs CARLSON: She knew she was going to pass away. She was ready …

DELMA: She knew that she was going to pass away. That is why she had to run away from hospital and come back and pass away at home.

Mrs CARLSON: She was trying to ask to come back as well?

DELMA: Yes. They did not let her, but she had to run away.

Mrs CARLSON: She could make that decision? There was nothing wrong? She was still lucid?

DELMA: Yes, she was able to talk and …

Mrs CARLSON: She could give her own consent if she could.

DELMA: When she came back, me and my sister were sitting down around the campfire place. She told me then, 'I want to tell you, my sister, that I am going to leave you both soon, any day'. That is what she said to me. 'I want to accept Lord Jesus before anything every happens to me', that is what she said to me. I had to teach her how to pray to accept Lord Jesus. The next day she passed away.

Mr CHAIR: When she came back here and she passed away, was she in pain as well?

DELMA: She was in pain, yes. She was in a lot of pain, but she was sitting with me around the campfire.

Mr CHAIR: There was no-one to help her here with the pain relief, no medicine for her pain?

DELMA: The nurse came over and …

Mr CHAIR: She did from here?

DELMA: Yes. I said, 'Have you got any painkiller to give her?'

Mr CHAIR: Was she able to help with any painkiller? She was able to give her something, but something to swallow, not to inject.

DELMA: Yes.

The INTERPRETER: [Kriol spoken.]

DELMA: [Kriol spoken.]

The INTERPRETER: Tablet.

Mr CHAIR: Much like a tablet?

DELMA: Tablet, yes.

Mr CHAIR: Some sort of pain relief.

That story of her leaving; has that happened before or is that the only time you can remember, someone leaving hospital to come back?

DELMA: Yes, some people do that.

Mr CHAIR: It happens, does it?

DELMA: Yes. Even when someone is ready to pass away, Aboriginal people come over and let the family—one of my aunties came to me and told me that she was going to pass away. I just looked at her.

The INTERPRETER: When they know they are going to die, they want to come home. Even if the doctor says they cannot come home, they run away. Half the time they come back. When the hospital realises that they have run away, they ring the communities to look for them …

Mr CHAIR: To check.

The INTERPRETER: … and then when they locate them through the clinic, then they tell the clinic staff to go over and monitor them, pain relief or whatever. But they do not let them—when they ask to come back in, most of the time they do not let them.

Mr CHAIR: If they were allowed to come out a bit earlier, then we might be able to monitor them a bit better; is that right?

The INTERPRETER: I reckon they need to explain too what they can access. A lot of our people do not know they can do that. They just think, 'I have to go to the hospital and die in the hospital'.

Mrs CARLSON: They would need an interpreter through every stage.

The INTERPRETER: Yes. Most of the time the doctor is just talking in medical jargon and all that, and most of the time they do not use interpreters.

Mr CHAIR: Delma, you have been around a long time. Barunga is your base?

DELMA: Yes, Barunga is my home, my daughter grew up here.

Mr CHAIR: You know Barunga really well.

DELMA: Yes.

Mr CHAIR: Barunga healthcare, is it better now or worse? Are some things better and some things worse than 10 or 20 years ago? What do you think? Has the healthcare here changed?

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: Just your clinic.

DELMA: I have never been much to the clinic. I only just go there and collect my medication.

The INTERPRETER: [Kriol spoken.] This time when I come back here, I go to the clinic for work, I walk in there and talk to them, but they do not even want to talk half the time. When I say, I am here for work, they just ignore you. I have heard from other community mob when they are sick at night, they go there for the on-call nurse or whatever and half the time they press the button and no-one comes.

DELMA: At this clinic, I had to argue with one of the nurses when my mum went to the CareFlight to Darwin. There was just one old man walking around. I said, 'I think your nurse had better check this old man. He doesn't look happy to me. He looks sick.' That is what I said to them.

Mr CHAIR: And what did they say?

DELMA: They had to check him out, that old man, and then he went to Darwin hospital.

Mr CHAIR: They put him on the CareFlight.

[Multiple people speaking.]

The INTERPRETER: And he ran away from the Katherine Hospital too and came back here and finished here. [Kriol spoken.]

DELMA: [Kriol spoken.]

Mr CHAIR: Then he went back to hospital.

The INTERPRETER: He did run away first, then he came back here for a couple of days, but the clinic mob took him back to the hospital and he passed away there.

Mr CHAIR: Do you know the details of that case? You do not know that person …

DELMA: We know his name.

Mr CHAIR: I was wondering if you knew what his illness was or why he went back?

The INTERPRETER: He had cancer too …

Mr CHAIR: Probably cancer?

The INTERPRETER: Lung cancer or throat cancer, because he used to smoke a lot and pick up the cigarette butts. I think he had throat cancer or lung cancer—one of them.

Mr CHAIR: When people finish up here, a lot of the time is it cancer or are there other things?

DELMA: Other things too—witchcraft too. They do evil witchcraft with Aboriginal people too.

Mr CHAIR: Really?

DELMA: When I was a health worker we had the old clinic over here, next to this (inaudible). I was a health worker; I was a trainee health worker. One of my cousin-brothers, his brother-in-law cut him with a stubby bottle. He broke that stubby bottle and cut him on the side. I witnessed this. When the nurse treated that wound, I had seen a grass—there were bushes, grass, coming out of that wound. I knew it was witchcraft.

Mr CHAIR: Does that kind of thing happen very often?

DELMA: That is the first time I had seen it, but I was a health worker. It does happen, I think, all the time.

Mr CHAIR: It is hard for a lot of us to understand a lot of the cultural laws, cultural relationships, some of the rules on country, the traditional rules. What we are trying to work out is if we make this VAD law whether or not it can help anybody in remote communities, whether they mind, whether they might use it or whether they will not use it.

The INTERPRETER: If they bring this law in for people when they are really sick and the doctor cannot do anything, no matter what medicine they give, but they will not get better …

DELMA: They are sick …

The INTERPRETER: If they say yes to this needle, if they have them only to make them finish before the finish (inaudible), you think about is it good for people? Some black people, is it good for them or it would be no good.

DELMA: That is normal out here.

Mr CHAIR: This is normal?

DELMA: Yes.

Mr CHAIR: It is okay if someone else uses it; even if you do not use it, you do not mind if someone else has a choice.

DELMA: Yes.

Mr CHAIR: It is okay for people to have a choice.

The INTERPRETER: [Kriol spoken.]

DELMA: Sometime it is really up to the patient whether you want to accept that needle or help that person (inaudible) …

Mr CHAIR: That is what the report people are saying too; it is up to the patient. If the patient wants …

Unidentified speaker: (inaudible).

DELMA: (inaudible) choice.

Mr CHAIR: Choice is the right word.

DELMA: Maybe the patient will talk to the rest of their family. If they do not want to take this needle, that is what the patient would say to the family.

The INTERPRETER: If they do decide, think about it, they will tell their family, 'This is my choice. I am the one who is suffering the pain. I want it. If I want to have it, I will have it.' Then the family will accept—everyone is not going to agree, but that is the person's choice.

Mr CHAIR: This has been really helpful, Delma, learning lots of things.

Matt, did you want to jump in with anything more?

Mr KERLE: I think you have covered it all really well.

I just want to say thank you for sharing.

Mr CHAIR: We learned a lot from talking, coming out and hearing what you have to say. With Lin's help especially, we learned a lot of things today.

Oly, is there anything you wanted to add?

Mrs CARLSON: No. I just want to say thank you as well for letting everybody know on the radio as well. They are out here talking. We just want to listen too.

DELMA: I should have got one of you girls to come on the radio.

Mr KERLE: Tomorrow when you do the radio, you can say, '(inaudible) I had all those Darwin mob, they came down and I talked to them.'

[Multiple people speaking.]

Mr CHAIR: That is actually a good point. If you, tomorrow, want to say, 'Call them on that number if you want to come', that would be very helpful because a lot of people are calling. Some people are writing and sending us a message. Some people are also calling the number. If they call and tell us what they think, it is very useful. It is very good as well. The number is on that list there. It is the second one. See the phone numbers at the bottom? There it is.

[Multiple people speaking.]

DELMA: And this one for the Lifeline that (inaudible).

Mr CHAIR: When you go on radio tomorrow, definitely say that you have had a talk with us, met us and we were okay.

The INTERPRETER: I was at the Barunga office with all the MLA—what do I call you?

Mr CHAIR: Parliament.

The INTERPRETER: Parliament mob, talking, trying to get ideas from all the community members about this VAD.

Mr CHAIR: It is really useful because people only come and talk to us if they trust us. They are more likely to trust us if they hear from you. If someone like Lin says, 'Hey, come and talk to them mob', then they are more likely to come. If you say to people—because we are still going out to other communities for the next few weeks.

The INTERPRETER: If you mention it tomorrow, then other mob will welcome them when they go to other communities.

DELMA: Okay.

Mr CHAIR: That will be helpful as well.

The INTERPRETER: [Kriol spoken.]

DELMA: Yes. They always hear me on the radio. (inaudible) Bulman and Weemol, everywhere.

Mr CHAIR: A lot of Roper Gulf, a lot of this area, will hear that radio, so it is good if you can talk to them and say that again. We will leave it with you.

Thank you. We really appreciate you taking some time and having a chat with us. We will let you know. We will keep you posted. We will let you know how things keep going. As we get further, we will make sure we let people know what is happening.

DELMA: All right, then.

The committee concluded.
